

Introducing the Nuffield Council on Bioethics

- contributing to the debate on the ethical conduct of research in global health emergencies

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Who are we?

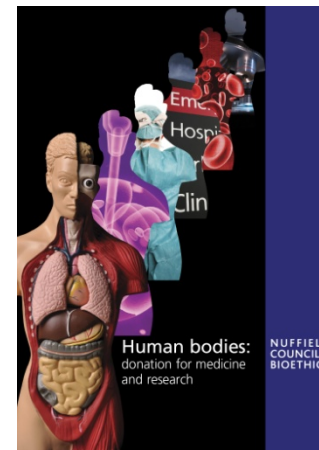
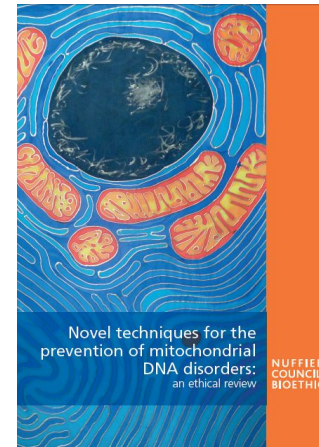
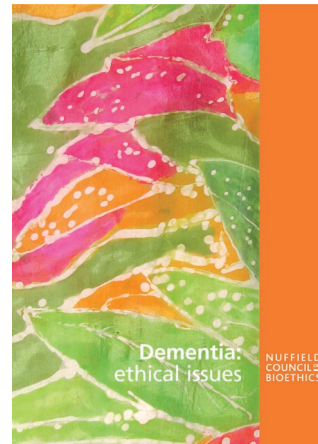
- **UK-based independent body, established in 1991**
 - not government sponsored (not a 'National Ethics Commission' as such)
 - appoint our own members, set our own agenda – influence depends on quality
- **Remit**
 - to explore ethical issues raised by developments in biology and medicine
 - engage with relevant stakeholders
 - make policy recommendations

How do we work?

Details will vary from project to project but will include:

- Establishing an expert working group – wide range of experience (including geographical reach where appropriate)
- Open consultative/deliberative activities
- Evidence-gathering of various forms, including review of literature and meetings with experts
- External review process

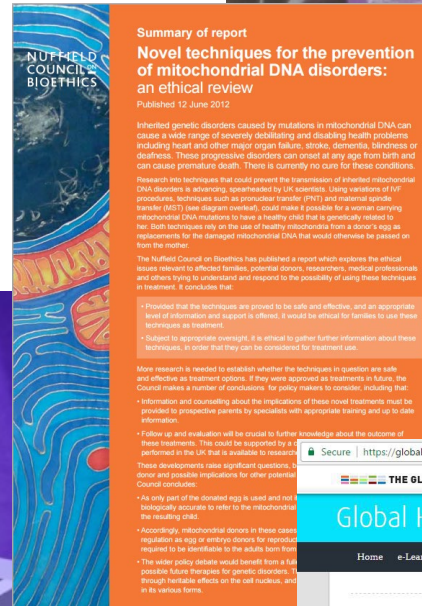
Publication of findings, analysis and recommendations: as a report



NUFFIELD
COUNCIL ON
BIOETHICS

... and in many other forms

- Booklets, magazines
- One-page for MPs
- Animation, films
- Teaching resources



Los niños y la investigación clínica

PRESESION AQUÍ PARA COMENZAR

ENGLISH

Recursos: Presionar aquí

Grupo de Discusión: Presionar aquí

Visión General del Curso

Duración:
El presente curso debe demorar de 45 - 60 minutos para concluir.

Certificado:
Se emitirá un certificado si se obtiene un mínimo de 80% en el examen final.

El presente curso de aprendizaje virtual ha sido formalmente reconocido por su calidad y contenido por las siguientes organizaciones e instituciones:



Research in global health emergencies: ethical issues

- Triggered by experiences of Ebola outbreak 2014-16:
 - Essential to improve evidence base
 - But real unease and uncertainty about what was ethically acceptable in such non-ideal circumstances
- Similar challenges in other types of health-related emergency / crisis

Progress to date

- Exploratory workshop Dec 2016
- Established international working group
 - six meetings so far
- Issued 'call for evidence' (nuffieldbioethics.org)
 - around 50 detailed responses with wide geographical reach
- Held series of roundtable meetings
 - frontline responders; funders; data and samples
 - Beirut, Dakar
- Final report – end of the year

Questions of scope

- **What counts as a ‘global health emergency’?**
 - Broad approach; ‘global’ in sense of need for solidarity-based support – not perceived threat
- **What counts as ‘ethical’**
 - Not just about ethical review ...!
- **What counts as ‘research’?**
 - Uncertain boundaries with public health surveillance, with evaluation, and in ‘hybrid’ activities

Emerging themes (1)

- **Community/stakeholder engagement and fair collaborations**
 - Issue of power and influence absolutely central to consideration of what is ‘ethical’
 - Engagement with affected communities essential – not a ‘nice to have’
 - Fair partnerships with researchers, institutions and governments in affected countries – real problem of ‘parachute’ research and lack of long-term capacity building

Emerging themes (2)

- **Study design, review & recruitment**
 - Not about taking shortcuts or lack of rigour – but about looking at what is appropriate for the context (even ‘heightened’ ethics)
 - Important links with stakeholder engagement
 - is this the right study for this location/population?
 - Is this the right design for this location/population?
 - ‘Consent plus’? – recognising that consent for any intervention is essential, but may not be enough

Emerging themes (3)

- **Role of front-line staff**

- Hierarchies and disparities in treatment of staff members – raises very strong feelings, and suggests real underlying problems with many international partnerships
- How to support frontline staff better in dealing with ethical challenges – recognition that ethical review doesn't answer all issues!

Emerging themes (4)

- **Data and sample ‘sharing’**

- What does ‘sharing’ mean in this context?

- How level is the playing field?

- How much control do local populations / participants have over the use of their data and samples?
 - Sharing data and samples can help advance science – but may also further disadvantage researchers in low income environments without the resources to act quickly. How can this be avoided?

Thank you!

nuffieldbioethics.org

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